People Leading Accessible Networks of Support (PLANS)

Family Support 360 Statewide Workgroup June 15, 2007 Pierre, SD

Chamber of Commerce

Brenda Smith brought the meeting to order at 8:30.



Members present:

Dawn Kellogg
Beth Hosek
Cindy Taber
Danny Spotted Eagle
Brenda Smith
Coleen Ronning
Melissa Flor
Tim Neyhart
Wanda Seiler
Dethi Hosek
Brenda Smith
Ronda Williams
Jennifer Seale
Ted Williams
Shirley Stirling
Janet Lemkuhl (for Sharon Sonnenschein)

Joey Younie (for Kristen Blaschke)

Others present:

Arlene Poncelet Stacey Mancuso Yvonne Reynolds
Dan (Danny's PA) Betsy Valnes Tarra Stoeser
Julie Johnson Dresbach Teri Sass Jean-Claire Hamblin

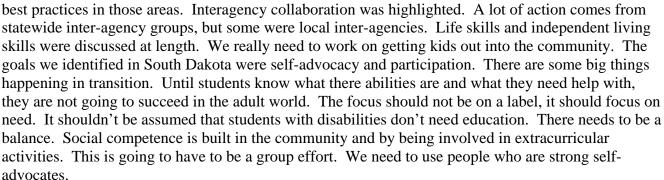
Introductions: Each workgroup member introduced themselves and stated where they are from.

Announcements: Brenda Smith will be substituting as chairman for Travis Arneson today.

Update on Transition Conference

Julie Johnson Dresbach was able to attend the National Secondary Transition Technical Assistance Center (NSTTAC) conference in North Carolina May 2-4. The Transition Project staff attended along with staff from the Department of Education and Department of Human Services.

It was quite unique because they had a lot of people from different backgrounds who work with youth. They were required to set goals in 5 areas and implement





Arlene reported that at its April 2007 meeting, the DD Council reviewed four Employment Proposals. The proposals covered areas of mentoring, training for supported employment, networking thru local organizations, developing localized tools for employers, employees and direct support staff, and turning volunteer positions into paid employment. The Council chose to provide funding to Human Service Agency in Watertown for their proposal that dedicated staff time to working with employers to



promote and change volunteer positions into paid employment for people with developmental disabilities.

During May 2007 the Council covered the registration fee and arranged for Meet Me Teleconferences for a series of 8 calls provided by TASH on Person Centered Work. With only about a weeks notice, PLANS workgroup members and ATCs were offered the opportunity to call in and listen to national speakers on the following topics: Roles Based Planning; Making a Difference: Activating Creative Partnerships with Direct Support Professionals; Discovery: The Foundation of Person-Centered Planning; The Challenge of Deep Quality in Person Centered Supports; Moving Toward Control and Community Inclusion: The Evolution of Personalized Supports; Sharing Lives Together: Housemates and People with Disabilities Share their Stories; Two Organizations Providing Individualized/Personalized Support; and Small Family/Self Governed

Collectives: Sharing the Learning About Working Toward Genuine Personalized Supports and the Roles Services Can Play. Arlene felt the sessions were excellent and if anyone is interested in any of the handouts they can contact her. Colleen Ronning and Brenda Smith both shared some thoughts on the information provided and thanked the Council for making these national speakers available to staff in a cost-effective way. Arlene added that if this is done again, that she would try to schedule additional time after each teleconference to allow for people who participate to stay on the line to share and discuss the information.

National Core Indicators (NCI) Update

The National Core Indicators first started in 1997. There are four different surveys in which SD participated: Adult Family, Family Guardian, Adult Consumer and Child Family. This is 2005 data that has now been published.

- The Adult Family survey was conducted by thirteen states and one local authority in 2005 and 2006. The Adult Family survey was given to individuals having an adult family member with disabilities living in the home. The largest factor between 2005 and 2006 was there where nearly twice as many responses in 2006. The information and planning section of this survey showed that the delivery of information to families seems to be insufficient, but the families that do get the information appear to be satisfied with the information they receive regarding services and supports for their family member. The access to and delivery of services and supports is the second section. The responses show that SD does well when responding to family requests for various services and supports in their region. However, families responded that access to special equipment and accommodations wasn't as satisfactory as in past years. One thing that was brought to attention was that data shows that SD doesn't appear to offer the appropriate translator services. Families' access to health services stayed about the national average. In the area of choice and control, SD is more than 10% below the national average. However, in the area of family choice of provider and support workers, the level of satisfaction increased in SD and nationally. Only 11.3% of South Dakotans feel that they have control and input over the hiring and managing of their support staff and 40.1% would like to have more control. In the Community Connections area, SD has made progress since the 2004 survey. Assistance with connection to supports in the community increased by 15.6% and assistance with accessing supports from family, friends and neighbors increased by 1.6%. The last area in this survey is Outcomes and Satisfaction with Services and Supports. Overall satisfaction with services and supports in SD is at a high level and 89% of families stated they feel that their family member is happy.
- The Family Guardian survey was conducted by 23 states and one local authority. This is the second time that SD has participated in this survey, the last time was 2002-2003. In the area of information and planning, SD performed well nationally but seemed to decrease on a state level. General satisfaction levels with staff appear to remain high. In the area of Access to and Delivery of

Services and Supports, SD remained average nationally in the area of health and safety concerning the family member's living and working environment. However, in the area of problems encountered by frequent changes in support staff there was a decrease in 2005-2006 but the level still remains high. In the area of choice and control, families were asked if they have control and/or input over the hiring and management of support workers, only 5.5% responded positively. However, when families were asked if they wanted control, 16.4% responded positively. In regards to the families' knowledge of how much money is spent by the agency on behalf of their family members, the results remain low and actually decreased from 33.6% to 30.8%. In the area of Community Connections, SD did well when compared to the national average however, satisfaction levels decreased marginally from the last survey. In the area of Outcomes and Satisfaction with Services and Supports, SD results continue to fall in the average range on the national level. There was a decrease of 4.4% in the families' knowledge of the process for filing complaints or grievances regarding services or the staff who provide the services. Although SD's satisfaction with the handling of the complaints and grievances is higher than the national average, it fell slightly from the previous survey.

The Adult Consumer survey was administered to people receiving multiple services from an agency and it was previously conducted in 2002-2003. SD had 537 usable surveys completed. The first area covered was Consumer Outcomes. In this area, SD scored fairly high, with little change since the last survey. In the area of in-home staff, SD notably improved in the number of people that choose who works with them. The percentage of South Dakotans who choose their daily schedule significantly increased. In the area of choice of work place, we increased in T^{O} the number of options that a person had, and decreased in the number of people who did not visit their workplace beforehand. SD continues to

increase the amount of choice offered in service coordinators. The next part related to relationships involving friends and family. The

number of friends and the amount of contact with friends and family continues to increase. When asked the question, "do you ever feel lonely?" 47.3% said "no or not often", as compared to only 9.6% in the previous survey. The next set of questions talked about satisfaction at work and home. There was a slight decrease in work site satisfaction and a slight increase in satisfaction concerning where people live. 91.7% of South Dakotans state that they are happy with their personal life. In the area of System Performance, SD made slight progress in relationships between the service coordinator and the person served. People have greater access to services, activities and new experiences. In the area of Health, Welfare and Rights, the results show that people generally feel safe in their home but not as safe when out in the neighborhood compared to the previous survey. Visits to the dentist are not happening as frequently as they have in the past, but happen significantly more often than the national average. Weight appears to be an issue as the percentage of overweight individuals is well above the national average. SD displays an increase in medications taken for mood disorders and anxiety and there was a decrease in medications taken for behavior problems. The area of respect and rights addresses advocacy, privacy, and interactions with their staff. Awareness of guardian/advocate significantly increased since the previous survey and freedom to be alone increased. Freedom to use the telephone anytime also increased. SD is well above the national average in the area concerning the privacy that people have in their homes and positive staff interaction with people served continues to be at a high level when compared to the national average.

The Child Family Survey was conducted with six states and one local authority participating. In the area of Information and Planning, SD ranked number one out of the seven involved. SD consistently did well compared to the national average but could improve on information distribution. South Dakotans have a high level of satisfaction in both participation and inclusion of important things in their lives and in the development of service plans for their family members. Overall satisfaction with staff continues to be high. In the area of Access to and Delivery of Services and Supports, SD ranked first out of seven. The satisfaction level increased for families needing support workers or translators to speak in their preferred language in SD. This still remains an area of much needed

improvement nationally. Access to special equipment and accommodations increased as did health, dental, and access to medications. In the area of Choice and Control, SD tied for third out of seven. South Dakota continues to struggle with this area on a national level but there was a slight improvement from the previous survey. Families have good awareness of how the agencies spend money on behalf of their children and seem to have decision making power over how that money is spent. In the area of Community Connections, SD ranks second out of seven. Although SD's results appear to be satisfactory compared to the national average, the satisfaction rates still remain low. The satisfaction level regarding access to community supports and activities, as well as help provided by staff, continue to increase. In the area of Outcomes and Satisfaction with Services and Supports, SD's 2007 results were considerably higher than the national average when asked if services had helped to keep their child at home. South Dakotans also reported a great level of satisfaction with the way complaints/grievances are handled and resolved when compared to the national average. SD's overall rank is first out of seven in the Child Family survey. SD's results are significantly higher than the national average in nearly every area. Although there remains areas of needed improvement, such as in the area of choice and control, SD is still making progress in improving services to families with children in the home.

Continuation Application

The grant has been sent in for renewal. Next year we will be entering year four of our five year grant. The year will run from October 07 to September of 08. In two years this grant funding will end, so Wanda is encouraging members of the group to provide additional input and ideas. Each year, ADD asked us to identify 3 new services for the grant. The three additional areas of focus for services for next year are supported employment, mental health services, and family strenthening services. Wanda asked that a copy of the Continuation Application be included with the minutes and distributed to the workgroup.

Break into the subcommittee groups. Subcommittees report back to the workgroup.

Housing: Arlene reported for the Housing group

Jean Claire is going to New Mexico, so we will get some national coverage for that. Each person in the group is going to commit to make a presentation in the community, such as for newspapers across the state on community housing, etc. We also need to remember to get them out of the "housing" mentality and into the community. Arlene spoke about the housing guide and how the website version will be updated more often than the hard copy. Feedback on the housing manual has been very positive thus far. There is an interest in sending the housing link to contractors in the state.

Transportation: Julie reported for the Transportation group

Julie talked about a brochure that the Department of Transportation puts out on information regarding public transportation in SD. Gas prices are driving up the cost of all transportation across the nation. Pine Ridge is trying to finalize a public transportation system. All the transportation information is going to be on the PLANS website. Cindy's story and picture with her car is also going to be on the website. They talked about the small movement in the United We Ride group. They would like to

invite Shelly Pfaff to come to the next PLANS meeting to come and report to the workgroup. Would like all the transportation vehicles used (i.e. daycare) etc identified. Rapid City is getting a new mayor and they hope that they don't have to re-educate that person on transportation. In Sioux Falls the para-transit route is cutting back, with more emphasis on fixed route transportation. This is going to be addressed at the SD Transportation Advisory Board.

Continuing Education: Stacey Mancuso reported for the group.

The Continuing Ed group thinks the pamphlet for self-determination developed by Betsy is a great start. They would like to put it on the website but edit it so that it is vibrant but not filled with an overload of useless information. Stacey had heard the word advocate once or twice in her life before becoming part of family support and is concerned that most people don't know what it means. The continuing education group is working on getting the information out in a user friendly way to South Dakotans. The goal is to make a webpage that will be a resource for all of South Dakota. The brochure will also be finished so that people that don't have internet access can still receive the information.

Independent Service Coordination - Carol Ruen

The feds are saying that we don't do this very well, so we are listening to that and trying to remedy it. We are only one of two states that does not offer choice for support coordination. How do we make this happen? The beauty of a pilot is that it is tested and it is trial and error. We are fortunate to have the funding from the Division and the Council. We developed written information for people who were interested in participating in the pilot project. We encouraged the pilot sites to be creative. This was our first step, so we got that developed and sent out. There are eight people who have indicated an interest in this program in the Aberdeen area. We want to recognize our two pilots, because this is taking time – more time than we thought – but we think it is okay. The pilot provides the luxury of changing something that doesn't work. Advance & VOA are the pilot sites. Carol is working on this with two other people from the Division. They want to be able to develop validity for the pilot. They came up with a service plan that is person centered. The biggest challenge is staying within the budget that they have been given. Wanda has approximated the hours for service coordination but they are being very careful and watching it so they have enough resources for it to be successful. That is the biggest concern and they are monitoring it closely. They want to provide the pilots with plenty of time to make it happen – looking at two years at this time. There are still a few unknowns, but that is the beauty of the pilot project. It feels like baby steps, which may be frustrating for the pilots, but really it is okay. This will make it easier to get input and to implement any changes. The goal is to make recommendations on how to make changes in service coordination in our state. We need to offer choice. The bottom line is that it is offering another way for people to advocate for themselves. We need to identify other community resources that may not have been tapped before.

Waiver Renewal

Donna Olivier informed the group that on March 1, 2007, DHS submitted the online waiver application to the Centers for Medicare and Medicaid Services (CMS). CMS looked over the application and decided that in order to continue the Family Support Waiver, the state must assign ATCs, also called the fiscal agents, as Organized Health Care Delivery Systems (OHCDS). We needed to change our plan and now on the waiver there is a spot for entities that are OHCDS. There have been some changes with the method of payment. Until recently the method of payment was: "Traditional Method of Payment" meaning that each provider furnishes the services directly, each provider has a Medicaid agreement, and Medicaid pays the provider directly. However, CMS felt that we were limiting provider enrollment and choice of providers. Now, in order to be considered an Organized Health Care Delivery System the agency must provide at least one waiver service utilizing their own employee and may contract with other qualified providers to

furnish waiver services. Payment is made directly to the OHCDS then the OHCDS reimburses its subcontractors. Providers of waiver services may not be required to affiliate w/an OHCDS, such arrangements must be voluntary and the state must provide for entering into the provider agreement. This would allow providers to bill directly and be paid directly by Medicaid. Our current ARSD (Administration Rules of South Dakota) doesn't allow for the open enrollment of providers that are not an ATC. CMS indicated that the provider qualification mandating that the waiver provider met ATC certification standards is not a reasonable expectation of a qualified provider. In order for us to submit our renewal and have it be approved, we had to submit a transition plan to make the necessary changes to the model. DHS has selected a Rules Workgroup to work on updating old rules, and writing new rules and provider qualifications for the changes to occur. The Division has put together a pretty aggressive timeline for the rule changes to occur. The Workgroup is hoping to meet the 12/4/07 Rules Committee Interim deadline for rule changes. The waiver did get approved for renewal on May 30, 2007 contingent upon our transition plan. The renewal period is for June 2007- June 2012.

Work Incentive Planning and Assistance (WIPA) Project

Cassie Stoeser is a Community Work Incentives Coordinator (CWIC) for the WIPA Project. Black Hills Special Services Cooperative administers this in SD for the Social Security Administration (SSA). Our goal is to work with people so they have more information when they do return to work. One new thing is that staff are now doing longer term follow-up with clients. Also staff are emphasizing the SSA work incentives. These are two big changes. All of the CWICs and benefits specialists work with other programs together so that they can look at the big picture to see how this will affect client's benefits. The important thing is that when people go back to work, they aren't going to lose their benefits right away. Cassie then discussed specific work incentives that are available to beneficiaries. The CWICs and Benefits Specialist provide services statewide. Please contact Cassie with questions and provide her contact information to

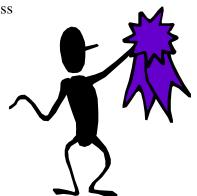
Quality - Wanda Seiler

others in need of these services.

The discussion began with the handouts on quality that were previously emailed to the workgroup. A review of the handouts was given by Brenda and Dawn. The main theme here is quality and choice. There is also a heavy emphasis on relationships. It is very important in our lives to focus on relationships. Quality is probably one of the most difficult things we face as part of our job responsibilities. The focus seems to be individuality and choice and control. Wanda asked everyone in the workgroup to give their perspective of quality.

Flipchart – Input from workgroup:

- Customer Service independent needs and responsiveness
- Can I choose my life
- Basic competencies workforce development
- Self Education knowledge
- Affordable healthcare
- Satisfaction with work
- To work on time
- Provide what they need
- Responsiveness, Supervisors
- Individual satisfaction
- Person's happiness
- Need/exceed customer expectations



- Community connectedness
- Free from abuse, neglect and exploitation
- Consistency and compassion
- Informed and involved
- Respectful attitude follow them, help them
- Hope for future
- Customer satisfaction
- Giving choices/meeting needs
- Work hard to get something accomplished
- Broad based how many, overall satisfaction, community resources

When looking at quality, you have to look at all the choices.

What Wanda wants is the "who, what, when and why" so that we may take this back to the PLANS staff and Donna Olivier.

If someone were going to assess the quality of the Family Support provider, WHO would that be? And HOW?

| WHO | HOW |
|------------|-------------------|
| Individual | Self assessment |
| | Confidential/Not? |
| | Face to face |
| | Open-ended |

The way to start is with a plan of care. And if you are not there, how are they going to know you were involved at all? The beginning of the process should be some conversation with the individual and guardians. The questions should be done face to face and open-ended.

| WHO | HOW |
|----------------|-------------------------|
| Interview | With prompts |
| Who's included | In person, paper, email |
| | Open-ended |
| | Plan/priorities |

What should we look for in files?

WHAT?

- Review documentation
- Case notes
- Documentation relates to the plan
- Needs meet assessment and modifications if necessary
- Personal outcome measures

Most people have several service providers. When we talk about supplying services, should we just be talking participants or other providers too? For instance, respite care providers, family support providers, VR etc. When should we do this and how often? How often should we come in and go thru this assessment process? Yearly sounds reasonable and practical. The next phase of this is really to lay out a process. We will get this in a document for you and work on it in the next meeting.

Family Support Council – Julie Dresbach and Stacey Mancuso

They are looking at how to merge the goals of PLANS and the FS Council. The FS Council meets once a quarter. They try to rotate where they meet at different times of the year. Stacey looked at the PLANS minutes from 3 years ago and is excited to see how much has changed and what has come about in the state. In FS Council, they talk a lot about transition - transition from birth to three years old and then three years to 21 years. The Council talks a lot about how the system works. They talk about the funding and where it comes from. The families and people who participate in the FS Council become educated and grow. They are not working on anything specific with legislation, but there has been time in the past that they have worked with the legislature and allowing the families to voice their opinions. At the meetings, they find out about national meetings that are going on, as well as youth activities. The FS Council also empowers parents and families. The coordinators come to many of the meetings. They have had the transition liaisons come and speak to the group.

Core Stakeholders Update – Dawn Kellogg

Yesterday, the Core Stakeholders Group had a conference call together. The Core Stakeholders are working on some of the things that have come up in PLANS that are out of the PLANS scope such as external case management, Good to Great, and agency of choice. During the conference call, the committee also discussed OHCDS and the Independent Support Coordination pilot. The proposal submitted by the Division and SDACBS was funded for another year by the DD Council. These issues are an ongoing focus and an ongoing need. There will always be another step to take and more to do.

Brenda would like to know if there are any joint projects we could work on with the FS council. She also asked for future agenda items.

The next meeting date is September 13th in Pierre at the Capital Lake Visitor's Center.

Brenda adjourned the meeting.